

A decorative border with ornate floral and scrollwork designs in each corner, framing the central text.

What You Need to Know about Me

**A Notebook for Families
and Caregivers**

What You Need to Know about Me: A Notebook for Families and Caregivers

This notebook was developed with the support of
a grant from
The South Carolina Alzheimer's Resource Coordination Center
as a joint project of
The South Carolina Respite Coalition
and
The Center for Child and Family Studies
USC College of Social Work
Columbia, South Carolina

June 2002

Notebook authors

Susan R. Carlton, Executive Director,
The South Carolina Respite Coalition
Norma S. Sessions, Training/Development Director,
The Center for Child and Family Studies

Acknowledgments

The authors thank the following for their immeasurable help in this work:

Frances L. Brannon, Alzheimer's Program Specialist,
S.C. Department of Health and Human Services,
Office of Senior and Long Term Care Services
Charmaine Cullen, R.N., Palmetto Lowcountry Hospital
Family members of persons with Alzheimer's Disease
Carla S. Greene, Project Coordinator, Quality Time Adult Respite Care
W. C. Hoecke, Respite Coordinator, Family Connection of South Carolina, Inc.
Paul H. Jeter IV, Executive Director, Alzheimer's Association,
Mid-State South Carolina Chapter
Terri Whirrett, Training and Technical Assistance Coordinator,
ARCH (National Respite Network and Resource Center)

This notebook may be copied in its entirety. However, please contact The S.C. Respite Coalition for permission: 803-935-5027. Appropriate citation must be given. The notebook is available in electronic form with appropriate credit included.

Table of Contents

Introduction	4
<i>How to Use the Notebook</i>	
The Basics	5
Emergency Information	6
My Home	7
My Medicines	8
<i>Prescription, Over-the-Counter, Herbal, etc.</i>	
My Health	11
<i>Medical Conditions and Allergies Mobility and Special Equipment</i>	
My Day	13
<i>How I Spend My Day Meals Bedtime</i>	
Things I May Need Help With	16
<i>Behaviors Communication Tips</i>	
My Story	21
My Faith	24
Photographs	25
Resources	27
Tell us what you thought of the notebook	29

INTRODUCTION

The purpose of this notebook is to provide a way for you, as a family member or other caregiver, to communicate with the people who provide respite care for the special person in your life who has Alzheimer's disease or other dementia. We hope that this notebook helps you to describe your loved one and his/her needs, so that the care can truly be individualized. Depending on the stage of the disease, your loved one may be able to help you complete some of the information.

You can include information about all aspects of your loved one's life and update the notebook as needed. You may also want to include photographs to help the respite care provider get to know your loved one. We suggest that you complete the notebook in **PENCIL** so that you can change information as your loved one's condition changes. We also encourage you to use the **Resources** section at the end of the notebook, particularly for information about **Advance Directives** and other important documents you may need. The more information you and your loved one gather and share with the respite care provider, the better that caregiving can be.

THE BASICS

My name: _____

How I like to be addressed: _____

The name I reply to right now: _____

Names of those who live with me:

_____ Relationship _____

_____ Relationship _____

_____ Relationship _____

_____ Relationship _____

My street address: _____

City: _____ **State** _____ **Zip** _____

Home phone #: _____

Directions to home (crossroads, landmarks) _____

EMERGENCY CONTACTS:

1) Name: _____

Relationship: _____ **Phone #s** _____

2) Name: _____

Relationship: _____ **Phone #s** _____

3) Name: _____

Relationship: _____ **Phone #s** _____

EMERGENCY INFORMATION**Doctor's name:** _____**Phone #:** _____**Hospital:** _____**Phone #:** _____**Medical Provider Payment Information****Guardianship:** _____**Social Security #:** _____**Medicaid #:** _____**Medicare #:** _____**Insurance name/#:** _____**Police Department** _____**Fire Department** _____**Poison Control** _____**Fire Extinguisher is located** _____**First Aid Kit is located** _____**My Advance Directives** (living will, health care power of attorney,
durable power of attorney) **are located** _____**We have a "do not resuscitate" form (EMS DNR) for
ambulances. It is located** _____

MY HOME

This home is heated by:

- Gas . . . The turnoff valve is _____
- Electricity . . . You turn it off by _____
- Oil . . . You turn it off by _____

Water is turned off by: _____

Utility company phone numbers:

Electricity _____

Gas _____

Oil Company _____

Water _____

Rooms I prefer to be in: _____

Rooms that are “off limits”: _____

Other information about my home: _____

MY MEDICINES
(Prescription, Over-the-Counter, Herbal, etc.)

Name of My Medicine	How Much I Take	When and How I Take It	What I Take It For	Side Effects to Look For
(Example)	One tablet 400 mg	Three times a day after meals (with water)	Diabetes	Dizziness, headache

MY MEDICINES
(Prescription, Over-the-Counter, Herbal, etc.)

Name of My Medicine	How Much I Take	When and How I Take It	What I Take It For	Side Effects to Look For
(Example)	One tablet 400 mg	Three times a day after meals (with water)	Diabetes	Dizziness, headache

MY MEDICINES
(Prescription, Over-the-Counter, Herbal, etc.)

Name of My Medicine	How Much I Take	When and How I Take It	What I Take It For	Side Effects to Look For
(Example)	One tablet 400 mg	Three times a day after meals (with water)	Diabetes	Dizziness, headache

MY HEALTH Medical Conditions and Allergies

Stage of Alzheimer's disease/dementia (if known):

Early_____ Middle _____ Advanced_____

Medical Condition	Current Status	Things to Watch For	What to Do

**MY HEALTH
Mobility and Special Equipment**

Things to know about moving or lifting: _____

Adaptive equipment and how to use it: _____

Written instructions for the equipment are located:

MY DAY

Usually, this is how my day is spent:

	Weekday	Weekend
6:00-7:00 A.M.		
7:00-8:00 A.M.		
8:00-9:00 A.M.		
9:00-10:00 A.M.		
10:00-11:00 A.M.		
11:00-12:00 noon		
Noon-1:00 P.M.		
1:00-2:00 P.M.		
2:00-3:00 P.M.		
3:00-4:00 P.M.		
4:00-5:00 P.M.		
5:00-6:00 P.M.		
6:00-7:00 P.M.		
7:00-8:00 P.M.		
8:00-9:00 P.M.		
9:00-10:00 P.M.		
10:00-11:00 P.M.		
11:00 P.M.-Midnight		

MY DAY
Meals

	BREAKFAST	LUNCH	SUPPER
Usual mealtime			
What I usually eat			
Foods I don't like or cannot eat			
Special preparations including utensils, dishes I like to use			
Where I like to eat			
What I like to do after my meal			
Snacks I enjoy			

I am allowed to have alcohol (beer, wine, liquor): _____ **yes** _____ **no**

If yes, how much? _____

MY DAY
Bedtime

The time I usually go to bed: _____

What I normally do before I go to bed: _____

Things I may need help with include: _____

Things that help me rest well include: _____

If I get up in the middle of the night, here are some suggestions: _____

If I have trouble going back to sleep, you might try: _____

If I wander, here are some suggestions: _____

If I get upset, here are some suggestions: _____

THINGS I MAY NEED HELP WITH

	Yes/No	What kind of help? Suggestions.
Dressing		
Bathing		
Shaving		
Eating		
Toileting		
Taking my medications		
Care of my teeth		
Care of my hair		
Going to bed		

THINGS I MAY NEED HELP WITH

Behaviors

I may try to _____

but not be able to do it. Here are some suggestions: ____

I may misplace my _____

(glasses, wallet, etc.). **It is likely to be** _____

If it is not there and we can't find it, a helpful thing to say is:

(for example, "We'll look for it tomorrow.")

If I start to argue with you, a helpful response is: _____

When I am angry, I usually say or do: _____

and a helpful response is: _____

Other general suggestions: _____

THINGS I MAY NEED HELP WITH

Behaviors

Some things may agitate me.

Television: (Yes or no? Suggestions...) _____

Stereo: _____

Computer: _____

Other people in the house: _____

Other things which are upsetting to me: _____

Suggestions: _____

THINGS I MAY NEED HELP WITH

Communication Tips

How best to communicate with me (to make sure I understand you): _____

Things I usually say to get my needs met:

When I need to go to the toilet	
When I want something to eat	
When I'm tired	
When I'm angry	

Other Communication Tips:

(check those that apply)

- Please accept what I say and use distraction rather than trying to make me understand or remember.**
- Listen to me, even if you cannot understand my words or gestures. I will be happier if you are at least paying attention to me.**
- DO NOT ARGUE.**
- DO NOT SAY: “Oh, you remember, we did that yesterday...” I probably don’t remember.**
- Don’t take things personally. What may seem like stubborn or manipulative behavior is more likely to be a result of my confusion.**
- Unless an item is dangerous, do not try to remove it from my hands. I may just want to hold your pocketbook and go for a walk. I’ll put it down soon enough.**
- I especially like touching or holding _____**

- If I can’t sit still, walk and pace with me. You are keeping ME company.**
- Other tips: _____**

MY STORY

I was born
(when): _____ **(where):** _____

My parent's names and what I called them: _____

Brothers' and sisters' names and what I called them: _____

I grew up (where): _____

After I finished school, I _____

The kind of work I did: _____

My spouse's name: _____

We've been married for (how long?): _____

My children's names: _____

Other important people in my life (friends, other relatives):

My pets: _____

My social/civic activities: _____

My hobbies: _____

Places I have traveled: _____

Things I am most proud of: _____

Things I cherish: _____

Things I enjoy remembering and talking about: _____

Things I'd rather not talk about: _____

Other important things about me: _____

MY FAITH

My faith is:

_____ **the most important thing in my life**

_____ **very important**

_____ **somewhat important**

_____ **not of interest to me**

I was raised in the _____ faith.

I converted to the _____ faith.

Church names I might mention: _____

My favorite religious song(s): _____

I like to hear you read from: (e.g., The Bible, devotional literature, etc.) _____

I pray before my meals: _____yes _____no

Praying with me is ___welcome ___OK ___not welcome

The way I pray/words I use: _____

PHOTOGRAPHS

PHOTOGRAPHS

RESOURCES

The South Carolina Respite Coalition 803-935-5027
Toll free 1-866-345-6786

Call for information on respite in your community and to become a volunteer advocate for respite; to receive information, newsletters, and updates; for more copies of this notebook and other resources; and to schedule a speaker on “The Benefits of a Break” for care receivers and caregivers or “Faith Community and Respite: next best thing to kin.”

Alzheimer’s Association Offices

Palmetto Chapter (Columbia offc) 803-722-3346; 1-800-636-3346

Charleston: 800-860-1444, Surfside: 866-8004460, Pee Dee: 866-334-1108

Upstate Chapter (Anderson offc) 864-224-3045; 1-800-273-2555

Greenville: 866-844-0995, Greenwood: 866-844-0992,

Rock Hill: 866-844-0993, Spartanburg: 800-908-9690

Call for information about Alzheimer’s disease and other dementias, support groups, choosing respite providers, choosing a nursing home or assisted living facility, ID bracelet for your loved one and much more.

Lt. Governor’s Office on Aging

Columbia

Toll free

803-734-9900

1-800-868-9095

*Call for phone numbers for your local Council on Aging, Area Agency on Aging (which sponsors the Family Caregiver Support Program), or Community Long Term Care (CLTC) office. They can send you a printed directory of Aging Resources, state and nationwide. Also, call to reach the S.C. Ombudsman’s office to request a packet on **Advance Directives** (living will, health care power of attorney, durable power of attorney). **Jon Cook or Dale Watson** can answer your questions about these documents.*

Community Long Term Care (CLTC) (get local # from # above)

Call for home care and respite services – for people who would have to be in a nursing home if you couldn’t provide care. Your loved one may be eligible now or later on. Get on the waiting list if you can.

S.C. Department of Health and Environmental Control (DHEC)

803-545-4370

Call to learn of citations (investigated complaints that were found true) of nursing homes and assisted living facilities. DHEC will explain how to write a letter under the “freedom of information act” requesting the information. Say that you are considering placing your loved one there for respite or long term care. The information will be mailed to you in about two weeks, free of charge.

DHEC (at 803-545-4204) can also send a “do not resuscitate” form (EMS DNR form) to your doctor. Anyone who does not want to be resuscitated (have his/her heart started or breathing tube put in) in an ambulance must use this. Advance Directive forms are not enough.

County Health Department**Look in the blue pages under
County Government**

Contact to learn about health and family support services. Also, ask about these booklets:

Blueprint for a Safe Home	#ML-007047
Caregiving - A Path with Heart	#ML-007061
Making Life Easier-DHEC Home Health Services	#CR-003090
Your Right to Make Decisions About Your Health Care	#ML-007017

American Association of Retired Persons (AARP) 1-800-424-3410

Call for brochures on changes to your house for someone with a disability. You do not have to be a member. Give the name and stock number:

Do-able, Renewable Home	#D-12470
How Well Does Your Home Meet Your Needs	#D-16270
Tools and Gadgets for Independent Living	#D-17035
Decisions about Help at Home for Alzheimer's Caregivers	#D-17623
Lighting the Way	#D-17460 (402)

Also, your local **Council on Aging** or **Vocational Rehabilitation office** can give you information about building a safe wheelchair ramp for your home.

National Association of Professional Geriatric Care Managers

www.caremanager.org (Internet) **1-520-881-8008**

Contact to find a social worker or medical person to set up the services you need. Insurance may cover these, but usually you have to pay a fee.

Information about Advance Directives (living will, health care power of attorney, durable power of attorney):

There are a number of places to get information about obtaining and completing these forms, including:

- **Your local Council on Aging**
- **The S.C. Ombudsman's office: 1-800-868-9095**
- **The Carolinas Center: 1-800-662-8859**

You can complete these forms yourself, but they must be notarized. Check with your local Council on Aging or bank for a notary.

If you need a lawyer:

- **S.C. Bar Association Lawyer Referral Service 1-800-868-2284**
- **Legal Services Corporation (free services) 1-803-799-9668**
- **National Academy of Elder Law Attorneys 1-520-881-4005**

They charge for a directory, but you can find the list free on the Internet at www.naela.org. Staff at your local library will look it up for you if you don't use the Internet.